Your Eyes and Graft-versus-Host Disease

Celebrating a Second Chance at Life Survivorship Symposium

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Ocular Graft versus Host Disease

What you should expect and what you can do about it
- from a survivor’s perspective

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Summary

• What is ocular GvHD
• Clinic findings
• Etiology
• Management
Graft vs. Host Disease

Donor
Host/recipient
New immune system forms
Attack host organs

Stem cells
Ocular GvHD

- Ocular GvHD affects 40-60% patients after allo-HSCT
- It can occur in setting of other chronic GvHD or independently
Acute ocular GvHD

Most often occurs within first 3 months after HSCT, but can be much later

- skin rash
- elevated liver enzymes
- digestive system dysfunction

The eyes can be significantly affected
Skin rash
White film covers the conjunctiva
The outer layer of cornea comes off
Chronic ocular GvHD

- Most often onset 5m to 24m after HSCT, but can be a few weeks to more than a decade or much later

- Can be isolated, first sign or later sign among other GvHD

- Can have mixed findings with acute ocular GvHD

  - Squinting all the time
  - Sunglasses indoor
  - Hands over brows
  - Poor functional vision
Blepharitis (red swollen lids, crusting)
Blepharitis (lid margin ulceration, foamy discharge)
Keratoconjunctivitis

- Not infectious conjunctivitis
- Erythromycin doesn’t really work
- Visine is TOXIC!
Keratoconjunctivitis  (damaged surface)
Filaments (they hurt a lot!)
Important glands on the inside of the lids are damaged as well.

Destroyed meibomian glands

Conjunctival scars result of inflammation

Kusne et al. 2017 Ocular Surface
The surface breaks down when healing is severely compromised
Cornea can perforate in just days
Keeps melting
What can we do about it?

First, understand the problems

Second, avoid preventable damage

Third, invest (your commitment) in management
Imbalance between damage and repair

Dryness
- Tear production
- Tear drainage

Inflammation
- Surface damage
- Redness

Not able to heal!
Would it go away?

- the most common question I get

Stem cells

So far, we can manage, but can’t get rid of it.
Avoid harm

- Avoid harmful behavior
  - Do not wear regular contact lens
  - Do not rub your eyes (this is for everybody!)
  - Do not dig for mucous or scratch the crusting with nails
  - Do not use redness reliever such as Visine, Opcon A, Naphcon A, Cleareyes
  - Do not use allergy eye drop such as Allaway, Zaditor
  - No contact lens wear
- Decrease screen time, take breaks
- Be very careful with make up and make up removal
Control the environment

- Modify environmental factors
  - Point air vents in the car away from your face
  - Humidifier ON! all the time when heat is on
  - Wear sunglasses
  - Sports goggles *(for motorcycling)* available to create “moisture chambers”

- Warm compress (without lid scrubs)
Keep the eyes wet

Dryness

1. Lubrication very frequently
2. Make more tears (hard to do)
3. Control the environment humidity
4. Punctal occlusion
Preservative-free lubricant
Preservative-free lubricant

• The correct frequency is to keep symptoms at minimum in between the drops

• One drop at a time is enough

• Recapping or not
Lubricant ointment at night

preservative-free
Make more tears

– Artificial tears (*preservative-free*)

– ReStasis and/or Xiidra
  – seem to work only in very mild cases
  – early start (prior to transplant) may have some benefit
  – not helpful in late stages

– Oral Pilocarpine (Salagen) or Cevimeline (Evoxac)
  – Often Rx for dry mouth
  – Induce tear production as well
  – Side effects can be moderated by careful titration in many cases
Punctal occlusion - close the drain

Dissolvable or non-dissolvable

Permanent - silicone

Punctal cautery


Marjan Mazouchi. Health & Medicine 2019
Control the inflammation

- Systemic immunosuppression and GvHD treatment
  - oral steroids, tacrolimus, sirolimus
  - watch out during taper!
- Garden variety of new GvHD treatments
- Topical steroids (appropriate taper and close monitoring)
  - If a steroid eye medication is prescribed, follow-up is a must
  - steroid strength
  - drop vs. ointment
- Serum tears (from your own blood)
  - labor intensive but often works well
  - Blood draw every couple of months
Therapeutic scleral lens

1. These are **NOT** regular soft or hard contact lens
2. They are fitted only by an optometrist who had special residency training
3. Your transplant doctor or GvHD eye doctor’s referral is needed
4. High cost, poor insurance coverage, steep learning curve, but life-changing result for many
5. Major ones are:
   - Boston Sight ([www.bostonsight.org](http://www.bostonsight.org))
   - GP lens Institute ([www.gpli.info](http://www.gpli.info))
   - EyePrintPro ([www.eyeprintpro.com](http://www.eyeprintpro.com))
BostonSight® PROSE

- Optic zone
- Epitheliopathy
- Artificial Tears
- Vault control spline
- Haptic zone
- Tears
- SCLERA
- CORNEA
1. The goal is to avoid having to do surgery if possible
   - corneal patch or transplant is **NOT** curative and is harder to take care of in the long run
   - amniotic membrane helps with healing but will not melt in days or weeks
   - none is comfortable

2. Avoid cosmetic eyelid surgery, eyeliner tattoo, lash extension, or laser vision correction
   - any tissue damage can increase inflammation
   - lid surgery and LASIK worsen dry eyes

3. Cataract surgery is an **exception**, it is necessary but needs to be done with extreme care
   - go to a surgeon with experience in oGvHD
   - pre-op and post-op care different from general population
Support the research effort

• 16 other trials in the US to date
• 12 completed/terminated/withdrawn - recruitment issue

• None FDA approved
What you can and should do?

- Recognize eye symptoms
  - You are busy, tired, hurt and fed up!
  - However nobody knows how your eyes feel before and after
  - Remember early diagnosis and treatment make a difference in outcome
  - Avoid getting to the point of no return
What you and your family can do?

- Advocate for diagnosis and treatment
  - **request** inpatient consult if needed
  - **volunteer** information to your transplant doctor about your eyes
  - **ask** for referral to **eye doctor experienced in GvHD** before and after transplant
  - **discuss** any **eye treatment or procedure**, and **systemic treatment change** with the specialist
What your eye doctors can do?

- Look for signs of ocular GvHD vs. other eye problems
- If you have a local eye doctor (general ophthalmologist or optometrist)
  - co-manage with specialist experienced in oGvHD
  - It is NOT just dry eyes!
  - It can rapidly progress into serious and irreversible situations!
- Initiate treatments as discussed earlier
- Promote the communication between all your doctors
  - Transplant service, dermatology, oral medicine, oncologist, PCP, everybody!
It is “we” and “us” working together!

First, understand the problems

Second, avoid preventable damage

Third, invest (commit) in management
Thank you!
Questions?

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